



PUBLIC HEALTH

**ALWAYS WORKING FOR A SAFER AND
HEALTHIER WASHINGTON**

HIV Reporting

May 10, 2006

Presentation To Address

- Review of notifiable conditions reporting
- Reasons for proposing policy changes
- Proposed policy changes
- DOH response to community comments and concerns

Review of notifiable conditions reporting

WAC 246-101-005

- Purpose – To provide information necessary for public health officials to protect the public's health by tracking communicable diseases and other conditions
- 70 diseases/conditions reportable by health care providers
- 34 diseases/conditions reportable by laboratories

Review of notifiable conditions reporting (cont'd)

Allows public health officials to:

- Treat people who are ill
- Provide preventive therapies for those who come into contact with infectious agents
- Investigate and halt outbreaks
- Remove harmful health exposures
- Assess broad patterns of disease and exposure

Review of notifiable conditions reporting (cont'd)

- Diseases/conditions are reported to and retained by name (exception – asymptomatic HIV)
- Case reports are forwarded to the Centers for Disease Control and Prevention (CDC) WITHOUT names for national data reports
- Diseases/conditions defined as “notifiable” evolve over time

Evolution of HIV/AIDS reporting

1980s

- Case reporting based on symptoms, conditions
- Cases were reported by a limited number of HIV specialists
- AIDS data were adequate to describe those who were infected
- AIDS and symptomatic HIV became reportable by name in WA

Evolution of HIV/AIDS reporting (cont'd)

1990s

- Lab component (low CD4s) added to AIDS case definition
- Therapies were developed to better treat disease
- Lab reporting became more critical
- AIDS data no longer described all with disease
- Low CD4s, detectable viral loads, and asymptomatic HIV (name-to-code system) became reportable in WA

Evolution of HIV/AIDS reporting (cont'd)

2000 and beyond

- More people than ever before living with HIV
- Lab results important for monitoring progression of disease along broad spectrum
- Challenges – To accurately count those living with HIV and describe their needs

Impetus for Rule Review

- Requirements of the federal Ryan White CARE Act
- Clear communications from the CDC regarding HIV reporting requirements
- Recommendations from the Council of State and Territorial Epidemiologists (CSTE), and endorsed by the CDC

CARE Act Requirements

- Federal funding for care and treatment based (in part) on HIV cases reported to the CDC
- Beginning FFY 2007, the states' portion of HIV (not just AIDS) will be used in calculating funding allocations.

CDC Requirements

Accept only HIV case surveillance data collected, reported, and maintained in state/local HIV/AIDS surveillance systems using confidential name-based methods

Impact of Federal Requirements

- A federal HIV care funding loss of **\$3 million to \$5 million annually** may result if Washington does not adopt a confidential name based HIV retention system.

Impact of Potential RWCA Funding Loss

DOH receives approximately \$11.2 million annually in CARE Act

- Almost \$3 million to fund HIV support services (e.g., case management) and
- Just over \$8 million to fund HIV treatment.

Impact of Potential Funding Loss (cont'd)

Example 1: \$3 Million Title II Reduction

- The almost \$3 million distributed to 14 consortia statewide would be eliminated.
- This funding supports essential services, such as HIV case management.
- Case management links nearly 2,000 HIV-positive individuals with primary medical care.

Impact of Potential Funding Loss (cont'd)

Example 2: \$5 Million Title II Reduction

- The previous \$3 million would be eliminated, and
- An additional \$2 million plus would be removed from AIDS Drug Assistance Program

Impact of Potential Funding Loss (cont'd)

To recap, these funding losses will likely lead to:

- Poorer health outcomes for Washington residents living with HIV/AIDS
- Jeopardize the HIV/AIDS service delivery infrastructure in WA State

CDC and CSTE Recommendations

- Laboratory reporting of all results from certain HIV-related laboratory tests to ensure reporting of prevalent cases quickly and efficiently into the surveillance system

Input Beyond the Reports/Recommendations

In addition to federal requirements and recommendations noted earlier,

- Two sets of stakeholder meetings were held in Seattle and Spokane (Dec. '05 and Feb. '06)
- Individual Meetings held with the Governor's Council, Title 1 Planning Council and Early Intervention Steering Committee and Statewide HIV Prevention Planning Group

Input Beyond the Reports/Recommendations (cont'd)

As a result of these meetings and written comments that were submitted, changes were made from draft 1 to the final draft

Proposed Rules Address Three Major Topics:

- State Health Department Names Retention
- Local Health Department Names Retention
- Expanded Laboratory Reporting

State Health Department Names Retention

- Authorizes state level retention of names of asymptomatic HIV cases
- Requires confidentiality systems to meet CDC standards
- Requires the Department to review security systems at the local level
- Requires the Department to report back to the Board in December 2007

Local Health Department Names Retention

- Authorizes local level retention of names of asymptomatic HIV cases
- Requires confidentiality systems to meet CDC standards
- Requires the local health department to cooperate with the Department's review of security systems

Expanded Laboratory Reporting

- Expands lab reporting requirements from limited HIV-related results (low CD4s, detectable viral loads) to all HIV-related results

Responses to Recommendations, Concerns, and Questions

Community Recommendations (Included):

- Include a report back to the Board
- Address anonymous testing in that report (ASO's)
- Prescribe technological security measures (ASO's, ACLU)
- Add that disclosure of information is only permitted as expressly permitted by those WAC sections (GACHA)

Community Recommendations (Not Included):

- Convene a community task force to review security and confidentiality protections (ASO's)
- Data storage on network drives should not be authorized (ASO's)
- Add a sunset clause if CDC no longer requires name retention (ASO's)
- Local level names retention should not be authorized (ASO's, GACHA)

Other Community Concerns and Comments:

- New System Should Not Undermine Confidentiality or Testing
- Disregards distrust of government
- Disregards level of stigma regarding HIV
- Security breach possible

Review of Proposed Policy Changes

1. Authorize state level names retention
2. Authorize local level names retention
3. Expand laboratory reporting

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